PARENT INFORMATION for Inconclusive Results from Repeat Newborn Screens for Cystic Fibrosis (CF)

The results of your baby's repeat screening test called an "IRT" to be elevated, but repeat screening on the DNA is still inconclusive for cystic fibrosis. Therefore the results continue to be reported out as "inconclusive". The Nebraska Newborn Screening Program recommends referral to an Accredited Cystic Fibrosis Center to explain the meaning of these results and further testing called a sweat test.

? If the results are still inconclusive why did we bother repeating the first test?

Most of the baby's that have inconclusive results on the first test will have normal results on the repeat test by 2 weeks of age. Repeat testing is less expensive and is easier for most families.

A small percent however, will continue to have "inconclusive" results on the repeat test. These babies are recommended to then have a "sweat test" at around 4-6 weeks of age. This test is considered the gold standard for diagnosing or ruling out cystic fibrosis. For more information on the sweat test, refer to the attached information sheet.

☛ What is the next step?

Be sure to follow your baby's doctor's instructions for getting the sweat test and going to the CF Center. The CF Center in Nebraska is located in Omaha and there is also a center in Denver, Colorado.

? What exactly is Cystic Fibrosis (CF)?

It is an inherited genetic disorder. A person inherits the disease from their parents. CF affects about 30,000 Americans and is not contagious. Children who have cystic fibrosis are born with the disorder, but often do not show visible signs of disease for weeks, months or even years. CF affects each person differently.

CF causes the body to produce an abnormally thick, sticky mucus that can clog the lungs, pancreas and other organs. This can lead to lung and digestive problems, which are treatable. A baby with CF will need regular medical care and a good diet.

With early diagnosis and treatment, children with CF may have improved growth and development, fewer hospitalizations and regular monitoring may prevent or reduce lung infections.

 What can I do to prevent these effects?

The most important thing you can do is to be sure that your baby goes in for further testing. You may have already done this, but now is also a good time to be sure your baby is covered by your health insurance provider.

This could be a false alarm, but if it turns out your baby has cystic fibrosis, new research and treatment has greatly improved the quality and length of life for those affected. As a result, children with CF should not be limited in their future goals and plans.

Sweat Test Appointment:

Date:_____Time:_____

Place:_____

(may be same as CF Center Appointment)

CF Center Appointment:

Date:_____Time:_____

Place:_____

_____

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For more information talk with your baby's doctor or you can contact the Nebraska Newborn Screening Program at (402) 471-6558. Also you may want to visit the Cystic Fibrosis Foundation's web site at www.cff.org.

Parent information brochure provided by the Nebraska Health and Human Services System, Newborn Screening Program in consultation with the Nebraska Cystic Fibrosis Accredited Care Center and the Nebraska Newborn Screening Advisory Committee November 2005.